

Multiple Chronic Conditions and Disabilities: Implications for Health Services Research and Data Demands

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Increasing numbers of Americans are living with multiple chronic conditions (MCCs) and disabilities. Addressing health care needs of persons with MCCs or disabilities presents challenges on many levels. For health services researchers, priorities include (1) considering MCCs and disabilities in comparative effectiveness research (CER) and assessing quality of care; and (2) identifying and evaluating the data needed to conduct CER, performance measure development, and other research to inform health policy and public health decisions concerning persons with MCCs or disabilities. Little information is available to guide CER or treatment choices for persons with MCCs or disabilities, however, because they are typically excluded from clinical trials that produce the scientific evidence base. Furthermore, most research funding flows through public and private agencies oriented around single organ systems or diseases. Likely changes in the data landscape—notably wider dissemination of electronic health records (EHRs) and moving toward updated coding nomenclatures—may increase the information available to monitor health care service delivery and quality for persons with MCCs and disabilities. Generating this information will require new methods to extract and code information about MCCs and functional status from EHRs, especially narrative texts, and incorporating coding nomenclatures that capture critical dimensions of functional status and disability.

Key Words. Chronic conditions, disability, functional status, comparative effectiveness research, quality measurement, health information technology, coding nomenclatures

At either end of the life span—and at all points in between—growing numbers of Americans are living with chronic conditions and disability (Institute of Medicine 2007; Centers for Disease Control [CDC] 2009). Many

factors contribute to this trend, including stunning therapeutic breakthroughs that preserve the lives of individuals, young and old, who would once have died from severe impairments. Other factors are less heroic, such as rising rates of overweight and obesity and stubbornly persistent tobacco use. The increasing recognition of multiple coexisting chronic health problems has generated its own acronym—multiple chronic conditions (MCCs)—and is attracting widespread notice among clinicians, health policy makers, and public health officials worldwide (Schoen et al. 2009). Three-quarters of the more than U.S.\$2 trillion now spent annually on U.S. health care goes to treating chronic conditions (Hoffman and Schwartz 2008).

Addressing health care needs of Americans with MCCs or disabilities presents challenges on many levels. Certain provisions of the American Recovery and Reinvestment Act of 2009 (ARRA), current public health initiatives (including development of federal Healthy People 2020 objectives), and approaches for fundamentally reforming U.S. health care all carry important consequences for persons with MCCs or disabilities. Given this broad context, this paper has two goals: (1) to underscore the need to consider MCCs and disabilities in performing comparative effectiveness research (CER) and evaluating quality of care; and (2) to suggest the data needed to conduct CER, performance measure development, and other health services research (HSR) to inform health policy and public health decisions concerning persons with MCCs or disability. The paper starts by defining chronic health conditions and disabilities.

DEFINITIONS OF CHRONIC CONDITIONS AND DISABILITY

Disease and disability are distinct concepts, although they often coexist (Iezzoni and O'Day 2006). Disease frequently (although not always) contributes to disability (e.g., osteoarthritis impairing ambulation). Disability, in turn, can precipitate secondary conditions or new diseases (e.g., spinal cord injury contributing to urosepsis or pressure ulcers). In May 2009, the CDC reported that the numbers of Americans living with disabilities is growing, and the three most important underlying causes are chronic health conditions—arthritis, back or spine problems, and heart troubles, in order of decreasing prevalence (CDC 2009). Adults reporting disabilities are 30 percent more likely than nondisabled respondents to describe being in fair or poor overall health (CDC 2008).

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Defining disease requires specifying the organ or organ system involved, the underlying pathology or pathophysiology, and an etiology or cause. By definition, chronic diseases persist over time, without cure or resolution. Here, the word “condition” refers broadly to health problems caused by some underlying disease or pathological process, even if the precise etiology is not explicitly specified (e.g., arthritis, chronic back pain). Many chronic conditions occur with aging. In 2005, among U.S. noninstitutionalized residents ages 0–19 years, 16.5 percent had one, 3.7 percent had two, and 1.2 percent had three or more chronic conditions (Paez, Zhao, and Hwang 2009). In contrast, among those ages 65–79 years, 20.2 percent had one, 21.5 percent had two, and 45.3 percent had three or more chronic conditions.

Specific meanings of the word “disability” vary by context. For example, the Social Security Administration has its own definition for disability determinations, as does the Americans with Disabilities Act for meriting civil rights protections (Iezzoni and Freedman 2008). Nonetheless, regardless of setting, assessment of disability typically requires information about physical, sensory, cognitive, or emotional functioning, and the extent to which individuals participate in daily activities in their homes and communities, facilitated by or impeded by environmental factors. In a framework supported by the Institute of Medicine (2007), the World Health Organization (WHO) defines disability as an “umbrella term for impairments, activity limitations or participation restrictions” conceiving “a person’s functioning and disability . . . as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including environmental and personal attributes (WHO 2001). Forty to 54 million Americans live with disabilities, and as with chronic conditions, disability rates also rise with increasing age: 6 percent among persons ages 5–15 years; 7 percent for ages 16–20; 13 percent for ages 21–64; 30 percent for ages 65–74; and 53 percent for ages 75 and older (Erickson and Lee 2008).

MEASURING QUALITY AND EFFECTIVENESS OF CARE

Development of performance measures and CER studies generally proceed disease by disease, ignoring the consequences of MCCs and disability (Vogeli et al. 2007). In a simple but compelling example, Boyd et al. (2005) applied evidence-based practice guidelines to a hypothetical 79-year-old woman with hypertension, diabetes mellitus, osteoporosis, osteoarthritis, and chronic obstructive pulmonary disease. To meet guideline specifications, the woman needed to undertake 14 nonpharmaceutical activities and consume 12 separate

medications in a regimen requiring 19 daily drug doses. Some recommendations contradicted each other, putting her overall health at risk. The numerous guideline requirements also neglected her preferences for different types of care.

As HSR researchers mobilize to perform ARRA-funded CER and develop evidence-based performance measures (e.g., to support performance-based payments), considering persons with MCCs or disabilities will become critical. Certainly, important approaches do exist for evaluating care provided to frail, clinically complex populations, such as measures developed for the Assessing Care of Vulnerable Elders (ACOVE) program (ACOVE Investigators 2007). Nonetheless, clinical and research leaders from across the country recently used a consensus process to outline a research agenda for improving clinical care for older persons with MCCs (Norris et al. 2008). Their report started by noting that almost half (48 percent) of Medicare beneficiaries over age 65 have three or more chronic conditions and 21 percent have five or more. Despite this, little information is available to guide treatment choices for persons with MCCs or disabilities because they are typically excluded from the clinical trials that produce the scientific evidence base (Norris et al. 2008). Furthermore, most research funding flows through public and private agencies oriented around single organ systems or diseases. Disease- or condition-specific therapies and management approaches may not apply to persons with MCCs or certain disabilities. Many performance measures representing processes of care therefore build in explicit inclusion or exclusion criteria, indicating which patients qualify for receiving the care process (Kahn et al. 2006).

If performance measures do not adequately account for patients' associated with MCCs or disabilities, clinicians or health care facilities might succumb to "risk aversion," trying to avoid clinically challenging patients (Birkmeyer, Kerr, and Dimick 2006; McMahon, Hofer, and Hayward 2007; Petersen et al. 2006). Early experiences from the United Kingdom's National Health Service pay-for-performance initiative for general practitioners, which began in 2004, suggests one possible outcome (Roland 2004; Velasco-Garrido et al. 2005). Physicians could "game" the incentive system by avoiding complex patients or reporting that these patients were "exceptions" to required clinical actions or outcomes. While widespread gaming failed to materialize, 91 practices (1.1 percent) excluded more than 15 percent of their patients from performance reporting (Doran et al. 2006).

In 2006, the Health Services Research and Development Service of the Veterans Health Administration held a state-of-the-art conference to explore management of MCCs and suggest future research directions in this area (Weiss 2007). The Department of Veterans Affairs (VA) confronts two imperatives

Table 1: Selected Research Topics Relating to Multiple Chronic Conditions (MCCs) from Veterans Health Administration State-of-the-Art Conference

Enhance understanding of gene and environment interactions that lead to common MCCs (basic and clinical science research)
Increase the evidence base of efficacy and effectiveness studies to support guidelines that apply to MCCs and social complexity
Advance work in outcome assessment, including measures of comprehensive care needs and optimized outcomes for patients with MCCs
Evaluate new health information technologies to support complex care management
Examine best practices in patient–physician communication strategies for care management decisions for patients with MCCs or with social complexity
Evaluate systems changes that organize care around MCCs and social complexity of illness management

Adapted from Weiss 2007.

forcing this focus: first, growing numbers of aging veterans with MCCs; and second, thousands of veterans from Iraq and Afghanistan who have returned home with complex physical, sensory, cognitive, and emotional disabilities. A literature review found large gaps in knowledge about MCCs, along with worrisome preliminary evidence (Vogeli et al. 2007). For example, complex disease–disease interactions might produce greater than expected disability levels in patients with MCCs; poor coordination of care among multiple specialists might contribute to high rates of adverse drug events and suboptimal quality of care; MCCs complicate the efforts of patients to self-manage their diseases; and single-condition disease management programs may fail to improve outcomes and lower costs for persons with MCCs. Conference members suggested research priorities to address the substantial knowledge gaps about caring effectively for persons with MCCs, including topics shown in Table 1.

DATA DEMANDS AND HSR ROLE

To address the issues raised above, HSR CER studies and research to specify performance measures will require readily available data sources that contain complete and accurate information about MCCs and disabilities. As new information infrastructures are built—under certain provisions of ARRA and public health data-gathering initiatives—HSR should lead evaluations of data quality. In particular, HSR studies could elucidate the potential for biased results should problems exist with data completeness and accuracy.

Because of space constraints, this data discussion focuses exclusively on data generated through clinical care or administering health care. Topics relating to health surveys, which are essential data sources especially for studies about population disability, are described elsewhere (Bradley, Penberthy, and Devers in press). In addition, although surveys provide essential data about population disability, various methodological challenges to capturing this information are undergoing active discussion among survey scientists. A recent report from Wunderlich et al. (2009) provides a more complete presentation of these concerns.

HEALTH INFORMATION TECHNOLOGY (HIT) AND HIT INFRASTRUCTURE

The promise of electronic health information for HSR—and more importantly for improving the safety, quality, and efficiency of health care—has bred cautious enthusiasm for more than two decades. However, with the exception of certain HIT-rich pockets within the health care delivery system (such as the VA's extensive clinical information system and some centers and delivery systems that have made substantial HIT investments over many years), much of this promise remains illusory rather than real. A survey in late 2007–early 2008 of physicians nationwide, found that only 4 percent had extensive, fully functional electronic medical record (EMR) systems, and just 13 percent had basic EMRs (DesRoches et al. 2008). A parallel survey of hospitals found that only 1.5 percent had comprehensive EMRs, while an additional 7.6 percent had a basic EMR system (Jha et al. 2009). The grander notion, of linking electronic HIT systems within communities to share individual health data across providers and advance public health goals, remains even more distant (Adler-Milstein, Bates, and Jha 2009). Beyond these implementation concerns, the evidence base supporting the value of HIT in improving care and increasing efficiency is ambiguous (Parente and McCullough 2009; Walker and Carayon 2009).

The ARRA authorizes federal expenditures of U.S.\$20 billion to advance the HIT infrastructure in different care settings nationwide, including supporting “coordination of care and information among hospitals, laboratories, physician offices, and other entities.” Theoretically, any effort that improves information exchange and care coordination should particularly benefit persons with MCCs or disabilities, who typically obtain care from multiple clinicians in different settings. HSR will be critical to assess whether this promise is fulfilled, as well as to devise ways to extract information from EMRs and other HIT sources to inform this research and meet other public health goals.

Potential Advantages of HIT

Simply having information in electronic form does not always ensure data will be complete and accurate, as suggested by experiences within the VA—long considered a pioneer in widespread EMR adoption (Kuehn 2009; McGinnis et al. 2009). Nonetheless, electronic algorithms can improve the completeness of documentation, a process that should assist with capturing data on MCCs and disabilities. A comparison of EMRs versus paper records at three large mental health centers found more complete recording of medications in EMRs, along with the additional benefit of timelier retrieval of information (Tsai and Bond 2008).

One study used clinical decision support tools and computerized physician order entry for medications within an EMR to extract information about health conditions and then to populate patients' problem lists (Galanter et al. 2009). Chart reviews determined that problems added by these electronic algorithms were 95 percent accurate. Another study used natural language processing to create an Automated Problem List among patients admitted to intensive care or cardiovascular surgery units (Meystre and Haug 2008). In the ICU, the completeness and timeliness of problem reporting improved significantly using this electronic algorithm. The Automated Problem List created from free text EMRs using natural language processing can also potentially improve the efficiency and accuracy of diagnosis coding (Meystre and Haug 2006). Natural language processing techniques applied to EMRs could provide timely information about brewing epidemic illnesses (Hripcsak et al. 2009) or medication complications (Wang et al. 2009).

Need for Coding and Classification Systems

Extracting information from HIT systems that can be easily compiled, compared, and analyzed requires a reliable and meaningful coding scheme. For several decades researchers have worked toward this goal. The Unified Medical Language System (UMLS), created and maintained by the National Library of Medicine (2006), aims to facilitate the understanding of biomedical terms and concepts by computerized information systems. UMLS offers several software tools, including the Metathesaurus, which is a large, multi-lingual vocabulary database that crosswalks and categorizes codes and concepts from other classification systems and code sets. The structural and semantic properties of UMLS are robust enough to explore relationships among different concepts (Patel and Cimino 2009).

Licensees of the UMLS Metathesaurus have access to the Systematized Nomenclature of Medicine Clinical Terms, generally known as SNOMED

CT (owned and maintained by the International Health Terminology Standards Development Organisation in Denmark), which is a multilingual terminology developed to retrieve and code clinical information reliably from EMRs (Cornet and de Keizer 2008). SNOMED CT is part of a suite of U.S. government-designated standards for the electronic exchange of clinical health information. Researchers within the VA have developed a method using coded clinical concepts from SNOMED to assess the quality of veterans' disability examinations with electronic algorithms (Brown et al. 2008).

Other widely used classification schemes include those developed by the WHO and groups with interests in specific scientific areas (e.g., laboratory testing, genetics). These various classification schemes often do not overlap, necessitating methods such as the UMLS Metathesaurus for cross-walking concepts and terms (Pathak et al. 2009). Some clinical areas have less developed classification approaches than do others. As consensus develops over the next several years about the best methods for coding clinical data from EMRs and other HIT sources, it will be important to ensure that the classification systems thoroughly reflect the full range of health conditions and disabilities.

As clinical information from HIT is coded and becomes more accessible for conducting research—or examining public health or health policy questions—linking these data to other information sources (e.g., data generated through administering health care delivery) could provide valuable insight (Luft 2010; Bradley, Penberthy, and Devers 2010). As described in other papers in this series (Lane and Schur 2009; Rosenbaum and Goldstein 2010), such linkages inevitably raise questions about privacy, along with other concerns (Diamond, Mostashari, and Shirky 2009). Nonetheless, these linkages may facilitate better understanding of the health care experiences of the heavy users of the system: persons with MCCs or disabilities.

CODING DIAGNOSES AND PROCEDURES

As noted above, efforts to summarize health information for populations requires data in clinically interpretable but analytically manageable bites. Since the mid-19th century, organizations interested in public health have recognized the need to produce information about health in meaningful and statistically manipulable codes. Today, the WHO governs worldwide efforts to code and classify health conditions, continually reviewing and revising their flagship nomenclature, the *International Statistical Classification of Diseases and Related Health Problems* (known simply as ICD). By international treaty, countries must report

causes of death using ICD. Therefore, the United States has reported mortality causes using ICD-10, the 10th edition, since January 1, 1999.

Several decades ago, however, U.S. clinicians, managers, and health policy makers sought coded diagnostic and procedural data for purposes beyond classifying causes of death. Specifically, U.S. users wanted coding systems for reporting “morbidity” and inpatient procedures. U.S. professional organizations developed a so-called clinically modified version of WHO’s ICD—the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM)—for these other purposes. The United States adopted ICD-9-CM for morbidity reporting (and for reporting hospital procedures) in 1979. Electronic administrative data systems contain slots for recording ICD-9-CM codes, and since 1983, these codes have supported Medicare’s inpatient prospective payment system (i.e., ICD-9-CM diagnosis and procedure codes generate diagnosis related group [DRG] assignments).

Over the ensuing years, the National Center for Health Statistics has maintained ICD-9-CM’s diagnosis classification, while the Health Care Financing Administration (renamed the Centers for Medicare & Medicaid Services [CMS]) updated the inpatient procedure classification. CMS also maintains another service and procedure classification system, the *Healthcare Common Procedure Coding System*, for coding services of physicians and other health care professionals and coding durable medical equipment and other items. Yearly, a government contractor updates the DRGs, adding the new diagnosis and procedure codes to the DRG classification algorithm.

Going beyond ICD-9-CM

Despite this updating process, ICD-9-CM has considerable limitations for today’s purposes. Most obviously, knowledge about disease has grown enormously since the 1970s, and new diseases, such as human immunodeficiency virus infections, have appeared. WHO has begun developing ICD-11 (Üstün et al. 2007), and many other countries already use ICD-10 (or their own clinically modified versions, as in Australia and Canada) for morbidity reporting.

U.S. professional organizations and coding experts have developed clinically modified versions of ICD-10’s diagnosis classification system (ICD-10-CM) and a newly conceived procedure classification system (ICD-10-PCS). These new classifications have important advantages in terms of clinical content and depth over their predecessors, which should substantially improve the ability to capture complete diagnostic information about persons with MCCs.

The U.S. government has delayed implementation dates for the new classification systems multiple times because of concerns about the feasibility and costs of moving from ICD-9-CM to ICD-10-CM and ICD-10-PCS. The new classifications have different organizational structures and thousands more codes than ICD-9-CM. Making the change will therefore require intensive staff and clinician training and modifications of computer software. In addition, critical administrative code-based algorithms will need reprogramming and recalibration with the new codes: examples include the DRGs, which as of October 2008 began transitioning to the more coding-intensive Medicare Severity-DRGs (MS-DRGs); and the Hierarchical Condition Categories (HCCs) used for Medicare Advantage plan payment. Nonetheless, on August 22, 2008, the U.S. Department of Health and Human Services (DHHS) finally published a proposed rule to replace ICD-9-CM with ICD-10-CM and ICD-10-PCS for electronic health information transactions covered by the Health Insurance Portability and Accountability Act of 1996. After a comment period, DHHS published final guidelines on January 16, 2009, specifying an anticipated implementation date of October 1, 2013.

HSR and ICD-10

International HSR researchers have already begun to explore the consequences of moving to ICD-10-based classifications. In 2005, investigators who use administrative data for HSR from Australia, Canada, China, Switzerland, the United Kingdom, and the United States met in Banff, Canada, to discuss these implications (De Coster et al. 2006). They identified various priorities relating to HSR, such as translating the code-based version of the Charlson comorbidity index and classification system designed by Elixhauser and colleagues into ICD-10 and redoing the Agency for Healthcare Research and Quality's Patient Safety Indicators using ICD-10-based codes. Beyond these types of activities, researchers will need to develop familiarity with ICD-10-CM and ICD-10-PCS to learn the strengths and limitations of these systems.

Although ICD-10-CM should theoretically improve the ability to represent the clinical conditions of persons with MCCs, concerns arise, at least initially, about data quality for this subpopulation. Coders overwhelmed by learning a new and massive classification scheme may not code all conditions comprehensively but instead code only those diagnoses required for administrative purposes (e.g., computing the MS-DRG or HCC). Both MS-DRGs and HCC assignments, however, require complete diagnosis coding, perhaps aligning payment incentives with the impetus for ensuring thorough coding of

MCCs. In fact, expectations about increases in diagnosis coding with implementation of MS-DRGs have led CMS to constrain payment increases to hospitals to avoid rewarding coding artifact rather than true increases in patient severity (Medicare Payment Advisory Commission 2009).

In the past, HSR researchers have analyzed longitudinal data to examine the completeness of coding of chronic conditions. Using Medicaid data from seven states, percentages of persons who had diagnoses coded in the next year after having had the code the previous year included the following: 80 percent for schizophrenia; 68 percent for diabetes; 58 percent for multiple sclerosis; 57 percent for quadriplegia; and 34 percent for cystic fibrosis (Kronick et al. 2000). Because these conditions do not disappear, their absence in the subsequent year suggested the level of incomplete coding. Efforts to identify persons with MCCs using coded administrative data must recognize this possibility.

CODING FUNCTIONING AND DISABILITY

WHO recognized that ICD (and even ICD-10) does not contain sufficient codes—or a meaningful conceptual model—for classifying concepts relating to functional impairments and disabilities. Thus, while ICD-coded data adequately capture diseases, they do not represent the disabling consequences of disease or disabilities from other causes (e.g., congenital conditions, injuries). In 1980, WHO approved a sister classification scheme to the ICD, the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). After a lengthy revision process, in 2001 WHO approved a revised system, the *International Classification of Functioning, Disability and Health* (ICF) (WHO 2001).

Explicitly recognizing the role of external forces—physical, social, and attitudinal environments—in precipitating or mitigating disability represents one of ICF's major contributions. In addition, ICF introduces participation in daily and community life as an explicit component of health, a concept that shifts the emphasis from strictly prevention or restoring functioning to maximizing functioning and well-being—perspectives consistent with public health goals in an aging society (Iezzoni and Freedman 2008). As noted above, ICF defines disability as an “umbrella term for impairments, activity limitations or participation restrictions” (WHO 2001). To respond to specific issues relating to children with disabilities, WHO recently published the *International Classification of Functioning, Disability and Health for Children and Youth* (ICF-CY), which aims to support reporting on the characteristics of child development, environmental factors that affect child development, and developmental delays (WHO 2007).

Use of ICF

For some reason, ICF has not gained widespread traction in the United States, although WHO and some member countries are using ICF in surveys and routine data collections (WHO 2007). In 2002 and 2003, the World Health Survey Program applied the ICF framework to generate population norms for disability prevalence and selected ICF domains across 71 countries. Efforts ongoing in Australia, Canada, Italy, India, Japan, and Mexico are streamlining and adapting ICF for routine reporting in home care, care of elderly populations, rehabilitation services, and disability evaluations. In the United States, ICF's use is concentrated among some groups of rehabilitation professionals, such as training occupational therapists.

Recognition of the ICF—if not its widespread use—may finally be growing in the United States. In its 2005–2006 activities, the Phase II Disability Work Group of the Consolidated Health Informatics (CHI) Initiative considered ICF for populating its Functioning and Disability Domain. (The CHI Initiative is a collaborative effort of the Departments of Health and Human Services, Defense, and Veterans Affairs to set uniform standards for electronic health information exchanges.) In a 2006 report, the National Committee on Vital and Health Statistics recommended ICF for a variety of purposes, noting its endorsement as a CHI standard and mapping to SNOMED CT terms.

In 2007, the Institute of Medicine (2007) recommended adopting ICF's conceptual framework in all U.S. efforts to monitor and measure population disability, although it acknowledged that a single definition of disability cannot meet all societal needs (e.g., disability insurance eligibility determinations). The IOM also recognized that aspects of the ICF coding scheme require further development. Finally, in 2009 the National Library of Medicine incorporated ICF and ICF-CY terms into UMLS, in partnership with WHO. This means that UMLS users can now link ICF terms with other classifications, terminologies, and vocabularies within UMLS.

Other Data Collection Approaches for Functioning and Disability

Meanwhile, for administrative purposes, CMS (and sometimes state Medicaid programs and private payers) has mandated extensive gathering of information about patients' functional status and disabilities in specific care settings. Nursing homes must gather this information using the Minimum Data Set (MDS); home health agencies must collect these data using the Outcome and Assessment Information Set (OASIS); and inpatient rehabilitation facilities (IRFs) must use the Patient Assessment Instrument (IRF-PAI) to collect these

data. MDS, OASIS, and IRF-PAI data are each used by CMS to set prospective payment amounts and in some instances to assess quality of care. Although each method collects similar types of information, the tools have important differences, and various efforts over the years to streamline and homogenize these data-gathering approaches have not yet succeeded.

Section 723 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 required the DHHS to make Medicare data about beneficiaries with chronic conditions readily available to researchers. The resultant database, the Chronic Condition Warehouse (CCW), selected its longitudinal cohort using the 5 percent national Medicare sample from 1999 to 2004, with all beneficiaries within that cohort tracked continually over time. From 2005 forward, CCW contains information for 100 percent of enrolled Medicare beneficiaries with the targeted conditions. CCW uses diagnosis and procedure data on Medicare claims to identify 21 chronic conditions (e.g., acute myocardial infarction, Alzheimer's disease, breast cancer, depression, diabetes, glaucoma, heart failure, hip fracture, osteoporosis, and stroke). Most important, all information gathered using the MDS, OASIS, and IRF-PAI about these beneficiaries is merged onto the CCW data. The 2006 CCW contained 2.3 million Medicare beneficiaries. Although this database offers a rich source of functional information, all these data are derived during provision of specific services, raising the potential for bias relating to differences in service availability or use by individual patients.

RESEARCH RECOMMENDATIONS

HSR methods and findings will play central roles as health care reform efforts proceed. As mandated in ARRA, the government is investing heavily in CER, with leading policy makers asserting that new evidence about relative treatment effectiveness could save both money and lives (Pear 2009b). Similarly, as White House and Congressional leaders write legislation to reform Medicare and health care more generally, tying reimbursements to quality (e.g., national benchmarks) has gained currency (Pear 2009a). Both efforts must consider those patients who are growing in numbers and generate the greatest costs—persons with MCCs and disabilities (Wolff, Starfield, and Anderson 2002). Wennberg and colleagues (2007) suggest that building pay-for-performance incentives around providing effective care to patients with chronic conditions offers a critical strategy for improving overall efficiency of U.S. health care. Some dispute whether such efforts will indeed reduce costs (Marmor,

Table 2: Research Recommendations for Health Services Research (HSR) Concerning Multiple Chronic Conditions (MCCs) and Disability

Develop methods to systematically assess the effectiveness, efficiency, and quality of care that explicitly consider persons with MCCs and disabilities
Study the consequences of MCCs and disabilities in all comparative effectiveness research
When developing quality indicators for performance measurement, explicitly consider concerns relating to persons with MCCs and disabilities
Invest in training HSR investigators for transition to ICD-10-CM and ICD-10-PCS coding, with special focus on implications for persons with MCCs or disabilities
After transition to ICD-10-CM and ICD-10-PCS, monitor the completeness and accuracy of coded data relating to persons with MCCs and disabilities
Develop collaborative efforts to explore using ICF and ICF-CY for coding functional status disability data from EMRs or from administrative sources, such as mandated post-acute care data sets
Develop methods (e.g., using tools developed or disseminated by the National Library of Medicine) to automatically extract information from EMRs to provide information on MCCs and disability
Create and evaluate new models of care for persons with MCCs and disabilities that aim to improve quality and efficiency of care for this population

Oberlander, and White 2009), and studies about the results of pay-for-performance initiatives offer mixed results (Greene and Nash 2009). Nevertheless, given their extraordinary costs and intensive clinical needs persons with MCCs or disabilities must figure prominently in any reform proposal.

As suggested in the examples listed in Table 1, persons with MCCs or disabilities raise a range of issues that HSR could address, beyond the specific topics emphasized here. Most of these suggestions, however, require preliminary research looking at basic questions about treatment effectiveness for persons with MCCs or disabilities. Table 2 lists research recommendations targeting the issues addressed in this paper. With population trends suggesting that growing numbers of Americans will live with MCCs or disabilities in coming decades, a concerted HSR focus on these individuals is essential. Improving the efficiency and quality of health care are obvious goals, but so too is the imperative of improving quality of life and health outcomes for individuals with MCCs or disabilities.

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REFERENCES

- ACOVE Investigators. 2007. "Assessing Care of Vulnerable Elders. Three Quality Indicators." *Journal of the American Geriatrics Society* 55 (suppl 2): S464–97.
- Adler-Milstein, J., D. W. Bates, and A. K. Jha. 2009. "U.S. Regional Health Information Organizations: Progress and Challenges." *Health Affairs* 28 (2): 483–92.
- Birkmeyer, J. D., E. A. Kerr, and J. B. Dimick. 2006. "Improving the Quality of Quality Measurement." In *Performance Measurement: Accelerating Improvement*. Committee on Redesigning Health Insurance Performance Measures, Payment, and Performance Improvement Programs, pp. 177–203. Washington, DC: The National Academies Press.
- Boyd, C. M., J. Darer, C. Boulton, L. P. Fried, L. Boulton, and A. W. Wu. 2005. "Clinical Practice Guidelines and Quality of Care for Older Patients with Multiple Comorbid Diseases: Implications for Pay for Performance." *JAMA* 294 (6): 716–24.
- Bradley, C., L. Penberthy, K. J. Devers, and D. J. Holden. 2010. "Health Services Research and Data Linkages: Issues, Methods, and Directions for the Future." *Health Services Research* 45 (5, part II): 1468–88.
- Brown, S. H., P. L. Elkin, S. T. Rosenbloom, E. Finkelstein, and T. Speroff. 2008. "eQuality for All: Extending Automated Quality Measurement of Free Text Clinical Narratives." *American Medical Informatics Association Annual Symposium Proceedings*: 71–5.
- Centers for Disease Control and Prevention (CDC). 2008. "Racial/Ethnic Disparities in Self-Rated Health Status Among Adults with and without Disabilities—United States, 2004–2006." *Morbidity and Mortality Weekly Report* 57 (39): 1069–73.
- Centers for Disease Control and Prevention (CDC). 2009. "Prevalence and Most Common Causes of Disability among Adults—United States, 2005." *Morbidity and Mortality Weekly Report* 58 (16): 421–6.
- Cornet, R., and N. de Keizer. 2008. "Forty Years of SNOMED: A Literature Review." *BMC Medical Informatics and Decision Making* 8 (suppl 1): S2.
- De Coster, C., H. Quan, A. Finlayson, M. Gao, P. Halfon, K. H. Humphries, H. Johansen, L. M. Lix, J. C. Luthi, J. Ma, P. S. Romano, L. Roos, V. Sundararajan, J. V. Tu, G. Webster, and W. A. Ghali. 2006. "Identifying Priorities in Methodological Research Using ICD-9-CM and ICD-10 Administrative Data: Report from an International Consortium." *BMC Health Services Research* 6: 77.
- DesRoches, C. M., E. G. Campbell, S. R. Rao, K. Donelan, T. G. Ferris, A. Jha, R. Kaushal, D. E. Levy, S. Rosenbaum, A. E. Shields, and D. Blumenthal. 2008. "Electronic Health Records in Ambulatory Care—A National Survey of Physicians." *The New England Journal of Medicine* 359 (1): 50–60.
- Diamond, C. C., F. Mostashari, and C. Shirky. 2009. "Collecting and Sharing Data for Population Health: A New Paradigm." *Health Affairs (Project Hope)* 28 (2): 454–66.
- Doran, T., C. Fullwood, H. Gravelle, D. Reeves, E. Kontopantelis, U. Hiroeh, and M. Roland. 2006. "Pay-for-Performance Programs in Family Practices in the United Kingdom." *The New England Journal of Medicine* 355 (4): 375–84.
- Erickson, W., and C. Lee. 2008. *2007 Disability Status Report: United States*. Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics.

- Galanter, W. L., D. B. Hier, C. Jao, and D. Sarne. 2009. "Computerized Physician Order Entry of Medications and Clinical Decision Support Can Improve Problem List Documentation Compliance." *International Journal of Medical Informatics* Epub.
- Greene, S. E., and D. B. Nash. 2009. "Pay for Performance: An Overview of the Literature." *American Journal of Medical Quality: The Official Journal of the American College of Medical Quality* 24 (2): 140–63.
- Hoffman, C., and K. Schwartz. 2008. "Eroding Access among Nonelderly U.S. Adults with Chronic Conditions: Ten Years of Change." *Health Affairs (Project Hope)* 27 (5): w340–8.
- Hripcsak, G., N. D. Soulaakis, L. Li, F. P. Morrison, A. M. Lai, C. Friedman, N. S. Calman, and F. Mostashari. 2009. "Syndromic Surveillance Using Ambulatory Electronic Health Records." *Journal of the American Medical Informatics Association* 16 (3): 354–61.
- Iezzoni, L. I., and V. A. Freedman. 2008. "Turning the Disability Tide: The Importance of Definitions." *JAMA* 299 (3): 332–4.
- Iezzoni, L. I., and B. L. O'Day. 2006. *More Than Ramps. A Guide to Improving Health Care Quality and Access for People with Disabilities*. New York: Oxford University Press.
- Institute of Medicine, Committee on Disability in America 2007. *The Future of Disability in America*. Washington, DC: National Academies Press.
- Jha, A. K., C. M. DesRoches, E. G. Campbell, K. Donelan, S. R. Rao, T. G. Ferris, A. Shields, S. Rosenbaum, and D. Blumenthal. 2009. "Use of Electronic Health Records in U.S. Hospitals." *The New England Journal of Medicine* 360 (16): 1628–38.
- Kahn, C. N. III, T. Ault, H. Isenstein, L. Potetz, and S. Van Gelder. 2006. "Snapshot of Hospital Quality Reporting and Pay-for-Performance under Medicare." *Health Affairs (Project Hope)* 25 (1): 148–62.
- Kronick, R., T. Gilmer, T. Dreyfus, and L. Lee. 2000. "Improving Health-Based Payment for Medicaid Beneficiaries: CDPS." *Health Care Financing Review* 21 (3): 29–64.
- Kuehn, B. M. 2009. "IT Vulnerabilities Highlighted by Errors, Malfunctions at Veterans' Medical Centers." *JAMA* 301 (9): 919–20.
- Lane, J., and C. Schur. 2009. *Balancing Access to Data and Privacy: A Review of the Issues and Approaches for the Future*. Working paper series of the German Council for Social and Economic Data (RatSWD).
- Luft, H. 2010. "Data and Methods to Facilitate Delivery System Reform: Harnessing Collective Intelligence to Learn from Positive Deviance." *Health Services Research* 45 (5, part II): 1570–80.
- Marmor, T., J. Oberlander, and J. White. 2009. "The Obama Administration's Options for Health Care Cost Control: Hope versus Reality." *Annals of Internal Medicine* 150 (7): 485–9.
- McGinnis, K. A., M. Skanderson, F. L. Levin, C. Brandt, J. Erdos, and A. C. Justice. 2009. "Comparison of Two VA Laboratory Data Repositories Indicates that Missing Data Vary Despite Originating from the Same Source." *Medical Care* 47 (1): 121–4.
- McMahon, L. F. Jr., T. P. Hofer, and R. A. Hayward. 2007. "Physician-Level P4P—DOA? Can Quality-Based Payment be Resuscitated?" *The American Journal of Managed Care* 13 (5): 233–6.

- Medicare Payment Advisory Commission. 2009. *Report to the Congress: Medicare Payment Policy*. Washington, DC: Medpac.
- Meystre, S., and P. Haug. 2006. "Improving the Sensitivity of the Problem List in an Intensive Care Unit by Using Natural Language Processing." *American Medical Informatics Association Annual Symposium Proceedings*: 554–8.
- Meystre, S. M., and P. J. Haug. 2008. "Randomized Controlled Trial of an Automated Problem List with Improved Sensitivity." *International Journal of Medical Informatics* 77 (9): 602–12.
- National Library of Medicine. 2006. "Unified Medical Language System Fact Sheet" [accessed February 28, 2009]. Available at http://www.nlm.nih.gov/pubs/fact_sheets/umls.html
- Norris, S. L., K. High, T. M. Gill, S. Hennessy, J. S. Kutner, D. B. Reuben, J. Unutzer, and C. S. Landefeld. 2008. "Health Care for Older Americans with Multiple Chronic Conditions: A Research Agenda." *Journal of the American Geriatrics Society* 56 (1): 149–59.
- Paez, K. A., L. Zhao, and W. Hwang. 2009. "Rising Out-of-Pocket Spending for Chronic Conditions: A Ten-Year Trend." *Health Affairs (Project Hope)* 28 (1): 15–25.
- Parente, S. T., and J. S. McCullough. 2009. "Health Information Technology and Patient Safety: Evidence from Panel Data." *Health Affairs (Project Hope)* 28 (2): 357–60.
- Patel, C. O., and J. J. Cimino. 2009. "Using Semantic and Structural Properties of the Unified Medical Language System to Discover Potential Terminological Relationships." *Journal of the American Medical Informatics Association* 16 (3): 346–53.
- Pathak, J., H. R. Solbrig, J. D. Buntrock, T. M. Johnson, and C. G. Chute. 2009. "Implementation Brief: LexGrid: A Framework for Representing, Storing, and Querying Biomedical Terminologies from Simple to Sublime." *Journal of the American Medical Informatics Association* 16: 305–15.
- Pear, R. 2009a. Medicare System Overhaul Proposed by Two Senators. *New York Times*, Thursday, April 30: A20
- . 2009b. U.S. to Study Effectiveness of Treatments—\$1.1 Billion in Fiscal Bill for Health Care Effort. *New York Times*, Monday, February 16: A1–10
- Petersen, L. A., L. D. Woodard, T. Urech, C. Daw, and S. Sookanan. 2006. "Does Pay-for-Performance Improve the Quality of Health Care?" *Annals of Internal Medicine* 145 (4): 265–72.
- Roland, M. 2004. "Linking Physicians' to the Quality of Care—a Major Experiment in the United Kingdom." *New England Journal of Medicine* 351 (14): 1448–54.
- Rosenbaum, S. 2010. "Data Governance and Stewardship: Designing Data Stewardship Entities and Advancing Data Access." *Health Services Research* 45 (5, part II): 1442–55.
- Schoen, C., R. Osborn, S. K. How, M. M. Doty, and J. Peugh. 2009. "In Chronic Condition: Experiences of Patients with Complex Health Care Needs, in Eight Countries, 2008." *Health Affairs (Project Hope)* 28 (1): w1–16.
- Tsai, J., and G. Bond. 2008. "A Comparison of Electronic Records to Paper Records in Mental Health Centers." *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care* 20 (2): 136–43.

- Üstün, T. B., R. Jakob, C. Çelik, P. Lewalle, N. Kostansjek, M. Renahan, R. Madden, M. Greenberg, C. Chute, M. Virtanen, S. Hyman, J. Harrison, S. Ayme, and K. Sugano. 2007. *Production of ICD-11: The Overall Revision Process*. Geneva, Switzerland: World Health Organization.
- Velasco-Garrido, M., M. Borowitz, J. Øvretveit, and R. Busse. 2005. *Purchasing for Quality of Care*. Berkshire, U.K.: Open University Press.
- Vogeli, C., A. E. Shields, T. A. Lee, T. B. Gibson, W. D. Marder, K. B. Weiss, and D. Blumenthal. 2007. "Multiple Chronic Conditions: Prevalence, Health Consequences, and Implications for Quality, Care Management, and Costs." *Journal of General Internal Medicine* 22 (suppl 3): 391–5.
- Walker, J. M., and P. Carayon. 2009. "From Tasks to Processes: The Case for Changing Health Information Technology to Improve Health Care." *Health Affairs (Project Hope)* 28 (2): 467–77.
- Wang, X., G. Hripcsak, M. Markatou, and C. Friedman. 2009. "Active Computerized Pharmacovigilance Using Natural Language Processing, Statistics, and Electronic Health Records: A Feasibility Study." *Journal of the American Medical Informatics Association* 16 (3): 328–37.
- Weiss, K. B. 2007. "Managing Complexity in Chronic Care: An Overview of the VA State-of-the-Art (SOTA) Conference." *Journal of General Internal Medicine* 22 (suppl 3): 374–8.
- Wennberg, J. E., E. S. Fisher, J. S. Skinner, and K. K. Bronner. 2007. "Extending the P4P Agenda, Part 2: How Medicare Can Reduce Waste and Improve the Care of the Chronically Ill." *Health Affairs (Project Hope)* 26 (6): 1575–85.
- Wolff, J. L., B. Starfield, and G. Anderson. 2002. "Prevalence, Expenditures, and Complications of Multiple Chronic Conditions in the Elderly." *Archives of Internal Medicine* 162 (20): 2269–76.
- World Health Organization (WHO). "WHO—ICF Application Areas" [accessed on February 28, 2009]. Available at <http://www.who.int/classifications/icf/appareas/en/>
- World Health Organization (WHO). 2001. *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization.
- World Health Organization (WHO). 2007. *International Classification of Functioning, Disability and Health: Children and Youth Version: ICF-CY*. Geneva, Switzerland: World Health Organization.
- Wunderlich, G. S., and Committee on National Statistics, Committee on Population, Division of Behavioral and Social Science and Education, National Research Council of The National Academies. 2009. *Improving the Measurement of Late-Life Disability in Population Surveys: Beyond ADLs and IADLs*. Summary of a Workshop. Washington, DC: The National Academies Press.